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Acceptability and feasibility of wearing activity monitors in community-dwelling older adults with dementia

Short Title: Feasibility of wearing activity monitors in people with dementia

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Declaration of Interest

We have no conflict of interest to declare.

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Abstract

Objectives: Measuring physical activity is complicated particularly in people with dementia, where activity levels are low and subjective measures are susceptible to inaccurate recall. Activity monitors are increasingly being used within research, however, it is unclear how people with dementia view wearing such devices, and what aspects of the device effect wear time. The aim of the study was to evaluate the acceptability and feasibility of people with dementia wearing activity monitors.

Methods: Twenty-six, community-dwelling, people with mild dementia were asked to wear an activity monitor (GENEactiv Original) over a one-month period. Perceptions of the device were measured using the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) 2.0, alongside qualitative interviews. Device diary and activity monitor data was used to assess compliance.

Results: Participants tended to find wearing the activity monitors acceptable, with only three participants (12%) withdrawing prior to the study end date. Participants were generally satisfied with wearing the devices as measured by the QUEST (Mdn = 4.4, IQR = 1.1). Four themes were identified that influenced perceptions of wearing the device: external influences, design, routine, and perceived benefits.

Discussion: Asking people with dementia to wear a wrist-worn activity monitor for prolonged periods appears to be both feasible and acceptable. Researchers need to consider the needs and preferences of the sample population prior to selecting activity monitors.

Keywords: technology, wearables, accelerometers, actigraph, adherence.

Key Points:

- 1) Activity monitors are both acceptable and feasible for people with mild dementia to wear.
- 2) The majority of people with dementia are able to wear an activity monitor continuously for a month duration with little issue.
- 3) Future research should consider how such devices effect the person with dementia's routine.

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Introduction

The use of activity monitors (e.g., accelerometers, actigraphs) as a means of capturing physical activity in people with dementia is on the rise,¹ in part due to the difficulty in accurately capturing subjective physical activity in cognitively impaired older adults. This is within the context of a lack of robustly developed questionnaires specifically for use in people with dementia.²

Current evidence suggests that people with dementia who do choose to wear activity monitors for research purposes find them acceptable.³ However, researchers have expressed concerns about the suitability of using activity monitors in representative groups of people with dementia.⁴ Certainly, cognitive impairment amongst older adults is associated with a higher likelihood of non-consent to wearing activity monitors.⁵ Others have noted that people with dementia may have issues with compliance (i.e. non-wear time), with one such study reporting compliance being as low as 46.3% in a 24-hour period in people with severe dementia.⁶ Reasons for non-compliance are not always clearly reported, though they may include repeatedly removing devices and refusing to wear devices at night.⁷

Technology should be user-need driven (e.g., weight, placement) to maximise compliance and uptake.⁸ Older adults without diagnosed dementia have previously expressed that they were satisfied with wearing such activity monitors,⁹ as well as rating them to be easy to use, useful and acceptable.¹⁰ However, their needs and perceptions of wearing such devices may be different from those with dementia.

Recently attempts have been made to engage with patient and public involvement to explore 'wearables' within dementia research.¹¹ However, there is an absence of literature describing in-depth the acceptability and feasibility of people with dementia wearing activity monitor technology within a research setting. This fits in more broadly with a gap in the literature

exploring the relationship between technology and dementia, particularly those living within the community,¹² which make up the majority of people with dementia (61.3%).¹³ We therefore aimed to explore, using mixed-methods, not only the adherence rates of wearing activity monitors, but also the views of people with dementia wearing activity monitors. Carer adherence and views were also captured to act as a comparison.

Methods

Participants

We enrolled community-dwelling, ambulatory, adults with dementia, aged 65 and above. Whilst there were no criteria based on dementia severity, participants were required to have capacity to consent. There was no other restrictions on comorbidities, health status or dementia type. Participants were also required to have a co-habiting unpaid carer who also participated. Participants were recruited from the geographic area of Sussex (South England). Health Research Authority ethical approval was obtained by the London - Brighton & Sussex Research Ethics Committee.

Procedure

Participants were identified either through self-referral or had previously expressed interest in participating in research studies. Informed consent was obtained from both the person with dementia and their carer. Capacity to consent was assessed in all people with dementia, with those lacking capacity being excluded from the study. Both the person with dementia and the carer were asked to complete a series of questionnaires (see below) before being given the activity monitor. All participants were provided with a device diary to make notes about when the device was removed, alongside guidance of the device functionality. Following one month or withdrawal from wearing the devices (which ever came first) a researcher

completed quantitative questionnaires about their satisfaction of wearing the device and physical activity levels. All participants were also invited to participate in dyadic qualitative interviews to explore their opinions about wearing the device, which were audio recorded. The activity monitors were collected at the end of testing. All participants were given a summary of their own physical activity participation after the completion of the study.

Measures

Activity monitor: The GENEactiv Original (Activinsights Ltd., Cambridgeshire, UK) is a tri-axial, $\pm 6g$ seismic, wrist worn acceleration sensor, which is small (36cm x 30 cm x 12cm), lightweight (16g), and waterproof. The device is black, with a black plastic sports strap. There are no other prominent design features, displays or interactive elements. The device is able to record up to 45 days without charging or downloading the data. The device has previously been shown to be valid measure of physical activity and sedentary time,^{14,15} and is commonly used in older adult populations.^{16–18} In the present study, the GENEactiv Original was set to have a sampling frequency of 20Hz. Both the person with dementia and the carer were asked to wear the device on their non-dominant wrist for the duration of the study. Participants were encouraged not to remove or interact with the device. Participants did not have the ability to review their activity habits in real-time. For the purposes of this study we used the data to estimate wear time. Physical activity levels, or any other indices from the activity monitor are not reported here.

Device diary: Both the person with dementia and carer were asked to complete a device diary, in which they could note the dates and times in which they removed the activity monitor, as well as reasons why.

Initial reactions: The carer and the person with dementia were both asked their initial views about the device after they were fitted. The researcher noted down this feedback and included verbatim quotes.

Questionnaires: Assistive Device Subscale of the Quebec User Evaluation of Satisfaction with assistive Technology 2.0 (QUEST)¹⁹ – An 8-item questionnaire developed to assess the satisfaction of using assistive technology was used to evaluate participants satisfaction of wearing the activity monitor during the study. As participants were not asked to interact with the device, or utilise its data, two questions were removed (i.e., *ease of use* and *effectiveness*). The QUEST was completed by the person with dementia and the carer.

The Montreal Cognitive Assessment (MoCA) test²⁰ – A short screening instrument of cognitive function. The MoCA was completed by the person with dementia only.

EQ-5D-5L²¹ – A generic measure of quality of life and general health status. The EQ-5D was completed by the person with dementia and the carer as a self-report instrument.

The Rapid Assessment of Physical Activity (RAPA)²² - A short questionnaire used to assess physical activity levels in older adults. The measure was completed by the person with dementia and the carer as a self-report instrument.

Qualitative interviews: The person with dementia (and their carer) were invited to complete in-depth dyadic interviews at the end of the study. The interviews were led by ST or GS. The interviews were used to explore the person with dementia's experiences and satisfaction with wearing the activity monitor during the study. The carer was also present in the interview to provide support to the person with dementia, and therefore formed a dyadic interview.²³

Analysis

Descriptive data were generated on participant characteristics (e.g., age, gender, diagnosis), the wear-time of the devices over the duration of the study (hours/day), and the total number of days with valid wear time hours (≥ 13 valid hours) based on device data. Calculations excluded the first and last day of recording. Classification of non-wear time was based per 15-minute block and based on the characteristics of 60 minutes window. Non-wear time was classified if for two out of the three axes the standard deviation of the 60 minute window was less than 13.0 mg, or the value range is less than 50g.²⁴ Processing of the data was run using GGIR package (version 1.5-12)²⁴ for R.²⁵

Data from the QUEST were analysed in line with previous guidelines.²⁶ For each device, individual item satisfaction scores were presented as percentages depending whether the participants scored 1, 2, and 3 or 4 and 5. A total QUEST score (from the assistive device subscale) was calculated by creating an average score (sum of valid scores/number of valid items). Summary scores (e.g. median (Mdn) and interquartile range (IQR)) were reported for the total QUEST score.

Initial reactions of the device from the person with dementia were coded into 'positive', 'negative' and 'neutral' comments by a single researcher (NF).

For the dyadic interviews, the first four transcripts were initially coded by two researchers independently (ST and GS). The coding was discussed between three researchers (GS, ST and NF) and an independent researcher (Dr Laura J Hughes) until a consensus on a coding framework was made. A single researcher (ST) then coded the remaining transcripts. Coding was periodically reviewed by other researchers, in which any new codes or queries were discussed. Themes, and subthemes were discussed amongst all researchers.

Results

Of the 61 participant dyads contacted, 25 refused, of which three (5%) explicitly stated that reason for refusal was due to not wanting to wear the device. An additional 10 dyads did not meet the inclusion criteria. Twenty-six participant dyads participated in the research, however a single carer refused to wear the device because of concerns of allergies to semi-precious metals. See Table 1 for participant demographics.

Dropout rates

Most people with dementia (n=23, 89%) and their carers (n=22, 86%) were able to wear the device for the full month (M= 28.0 days, SD = 8.7), which was confirmed via the collection of the device at the end of the study period.

Based upon the device diaries, three participants with dementia stopped wearing the device after 1, 6 and 7 days respectively. Of these participants, only one withdrew because they disliked wearing the device. The same carer dyads stopped at a similar time as the care recipient.

Technical issues

All devices were returned intact, with no evidence of damage. A total of eight devices across all participants experienced an unknown technical issue in which data stopped recording prior to the devices 30 days recording capacity. A minimum of 23 days of data were captured in all devices that had a technical failure.

Adherence and non-wear time

Based on the device diaries, seven people with dementia and five carers took off the device at some point during the study. Device data revealed that people with dementia and the carer wore the device for an average of 23.1 hrs/day and 23.8 hrs/day respectively. Nearly every day the device was worn provided a valid day's data, based on the requirement of 13 hours of wear time. There was no significant difference between the percentage of valid days between the person with dementia (98%) and the carer (100%) ($Z = -1.46$, $p=0.14$). See Table 2.

Initial reaction to devices

Of the initial comments made by the person with dementia, there was roughly an equal split between positive ($n=17$) and neutral ($n=17$) comments. There was a tendency for more negative comments ($n=24$) which typically criticised the aesthetics of the device.

QUEST

Both the person with dementia and the carer were least satisfied with the dimensions and comfort of the device. The majority of people with dementia were quite satisfied or very satisfied with all items on the QUEST. See Table 3.

The total QUEST scores confirmed that both the person with dementia ($Mdn = 4.4$, $IQR = 1.1$) and carer ($Mdn = 4.0$, $IQR = 1.2$) were generally satisfied with the device. On average, the person with dementia was significantly more satisfied with the device compared to the carer ($Z = 2.15$, $p = 0.03$).

Most and Least Important Features

Comfort was deemed as the most important feature of wearing the device in both the person with dementia (n=14, 56%) and the carer (n=9, 36%). Weight, ease in adjusting and durability were seen as the least important feature of the device for the carer (n=6, 24%), whilst weight and durability were seen as the least important feature in the person with dementia (n=6, 25%).

Qualitative interviews

Four key themes were identified in relation to the views of wearing the activity monitor; 1) Routine, 2) Design, 3) External Influence and 4) Perceived benefits. Example quotes and summary of themes can be seen in Table 4.

Routine

A common theme that appeared was the notion of routine. People with dementia commented that they were more aware of the device when it resulted in deviations from their normal routine.

Many participants who took part in the study were used to wearing a watch. The routines associated with wearing a watch, such as taking it off before going to bed or removing it before bathing, were somewhat disrupted by wearing the device. In part, this was because participants were instructed to wear the device at all times, including whilst bathing and whilst at night. Therefore participants often commented that the device was brought to their attention when routines associated with wearing a watch were disrupted. Sometimes this led

to them reverting to their normal routines, such as taking their device off before washing as they would do so with a watch.

It was noted that despite this awareness whilst disrupting normal routines, participants noticed the device less after a period of adjustment.

Design

The design of the device featured heavily including comments about appearance, weight, materials, dimensions and comfort. The majority of participants found that the design was acceptable with only a few minor changes suggested.

One of the most frequently raised suggestions was that the device would benefit by also functioning as a watch. For those who already wore a watch, this would have assisted in resolving some issues with changes to participants' routine, as it would mean they would not have to choose between removing their watch or wearing their watch alongside the activity monitor.

Many participants suggested that having a device which could also function as a watch would make the wearing of the device more convenient and therefore more acceptable to them.

External influence

Another theme which emerged was the notion of external influence and the role of others in wearing the device. The majority of people with dementia stated that family and friends did not often comment on the device but when they did, these comments were inquisitive and

brief. Most importantly, these comments did not deter the person with dementia from wearing the device.

The theme of external influence also emerged when considering the role of the carer in encouraging or reminding the person with dementia to keep the device on. Interestingly, many caregivers noted that they did not have to encourage or remind the person with dementia to continue wearing the device.

External influence was not something which appeared to have a great effect on whether the person with dementia continued to wear the device once it had been worn for a period of time. However, external influence may have had a role to play in the initial motivation to wear the device. Some participants commented that they were motivated to wear the device because of the research objectives or because a family carer also wanted to take part in the research.

Perceived benefits

People with dementia identified that there were benefits to wearing the device, both for themselves and for others in the future, which may have encouraged them to wear the device.

A number of participants also identified that they were participating because they wanted to find out about their own physical activity habits in addition to contributing to dementia research.

Discussion

This study set out to explore the feasibility and acceptability of wearing an activity monitor for a prolonged period of time (1 month) in people with dementia. We found high feasibility and acceptability of wearing the monitor in our study population. They were willing and able to wear the monitor and did so for more than the time needed for useful measurements to be made. The majority of people with dementia (n=23, 89%) were able to wear the device for the full duration of the study. Participants identified that there was scope to improve the devices design, but participants were generally satisfied with the device.

Both the device diary and the GENEactiv Original confirmed that there were periods in which the devices were removed during the study, though this equated to less than one hour per day over the captured period. Researchers generally require 10 hours of wear-time to estimate physical activity,²⁷ though others have recommended that 13 hours of wear time is needed to ensure accurate estimates of physical activity.²⁸ However, it should be noted that these are based on younger participants who were cognitively healthy and therefore wear time requirements may differ to older adults with dementia. Based on the more conservative cut-off, on average participants had 26 days' worth of valid data. Overall there were no differences between wear time between the carer and the person with dementia. Only two people with dementia did not achieve the recommended minimum valid days of six consecutive days,²⁹ both of which were participants who stopped wearing the device prior to six days. The ability for the majority of people with dementia to wear the device for the duration of the study, supports recent findings from the DREAMS-START study, which found that only 1/62 were unable to wear an actigraph device for more than 7 days at baseline.³⁰

From the qualitative interviews, four key themes were found to influence participants' perceptions of wearing the device. The extent to which the device fit into the individuals' routine prominently featured in the interviews. Participants' struggled with the fact that they

did not have to take it off the device at night or whilst bathing because this was different to their routine when wearing a watch. As such, there appeared to be an initial adjustment period in which participants were able (or not) to accommodate the device into their lives. The importance of fitting with individuals' routines ties with the Alzheimer's Society's recommendations when selecting assistive technologies.³¹ In line with this, participants requested that a watch function on the device would be useful because it could allow them to wear a single wrist based item. Older adults have previously expressed an interest in wearing wrist worn activity monitors over waist worn devices.⁹ The design of the device was often commented on, however the person with dementia identified that comfort was the most important aspect of the wearing an activity monitor. Unlike previous research in cognitively intact older adults with commercially available devices,⁹ the participants did not criticise the devices for being 'fiddly', which is likely due to participants not having to remove the device for any reason. Participants also identified that their perceptions of the device were affected by the perceived benefits of wearing the device. There was a subgroup of participants that were primarily driven by finding about their own physical activity habits (which were provided at the end of the study). These participants often requested that the device could show them real time activity levels. This is certainly possible with activity monitors, however this could only be implemented in research which aimed to increase physical activity using the activity monitors, as real-time feedback could influence physical activity behaviours. Therefore, within the context of the present research, where the activity monitor is used for the purposes of capturing physical activity alone, the inclusion of real-time feedback is not feasible.

It should be noted that participants were asked to wear the device for a month, which is longer than the minimum recommended wear-time of six consecutive days.²⁹ The decision of a longer wear time was selected considering the potential that people with dementia may be

susceptible to short term barriers to participation (e.g., acute illness, bad weather), but also to be able to highlight that people with dementia are able to wear such devices for extended periods of time if necessary, without effecting data quality. It is worth acknowledging that many activity monitors are further limited by battery life or memory, thus require regular engagement to charge or extract data from the device. In light of this, if an activity monitor has a three-day battery life, it would require the participants (or researcher) to charge the device every three days, for the duration of the study. This would likely increase non-wear time and non-compliance, as it would require participants to remember to charge the device, but also to put back on the device afterwards. This is particularly problematic for people with dementia as prospective memory, the memory of future intentions, is significantly impaired.^{32,33} As such, selecting an activity monitor that meets the researchers needs but also limits participant burden is essential. The need for the device to be charged (or data extracted) during the study maybe unavoidable in some circumstances (e.g. very long wear periods), and therefore researchers should consider facilitating this process rather than being reliant on the person with dementia.

It is important to recognise that eight devices experienced some form of technical fault, in which the device did not capture data for the full duration of the study. Unfortunately, we are unable to determine the reason why these devices did not record for the full duration, which could be due to an internal error in the device, researcher error (e.g. device not fully charged), or some other factor. Importantly, all devices that experienced such a technical failure were able to record for 23 days without any problems, and therefore would capture enough data to meet most minimum wear time requirements.^{28,34} Irrespective, it is important to consider that there is always likely to be a proportion of missing data when using any measurement tool, and this is no different with accelerometer technology. Considering this, researchers should account for potential missing data in estimating required sample sizes in future studies.

An important limitation of the study surrounds the generalisability of findings. The sample used in the present study tended to have a milder severity of dementia (mean MOCA = 17.7), and therefore is important to recognise the findings presented here may not reflect those with more severe dementia. Subjectively, participants rated their quality of life largely inline within age-related population norms,³⁵ with only a small number reporting any physical complaints. The majority of people with dementia and the carers were considered underactive (52.0% and 60.0%, respectively), though this is higher than reported in other community older adults (46.0%).³⁶ As such, the findings may not reflect the opinions of those who are more physically frail or a highly sedentary/active sample. Another limitation of the study is that the findings are based on participants commenting on a single device and therefore may affect the type of responses received, particularly in a sample that had little experience of using other wearable technology. For example, as participants did not need to charge the device and lacked the awareness that this needed in other devices, meant that no participants commented on the benefits of such a feature. The GENEactiv Original used in the present study conforms to many previous recommendations of wearable technology in dementia, namely that the device was robust, discreet (i.e., like a wristwatch) and low-maintenance.¹¹

Conclusions

This study suggests that wearing an activity monitor is both feasible and acceptable for people with dementia. Whilst there are several aspects of the GENEactiv Original device that could have been improved, the majority of participants were able to continuously wear the device for up to one month with little issue. Future research should consider the needs of people with dementia when selecting activity monitors for use, with a particular emphasis on ensuring that it does not interfere too much with their routine. Importantly, further research

needs to explore the feasibility of implementing such devices in more severe cognitive impairment.

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Table 1. Demographics of carer (n=26) and person with dementia (n=26).

	Person with dementia		Carer	
	Mean (SD)	N (%)	Mean (SD)	N (%)
Age	79.8 (5.8)		76.4 (5.9)	
MOCA (higher is better, 0- 30)	17.7 (3.7)			
Gender: Male		16 (61.5%)		7 (26.9%)
Dementia diagnosis				
Alzheimer's Disease		13 (50.0%)		-
Vascular Dementia		1 (3.8%)		-
Mixed Dementia		8 (30.8%)		-
Lewy Body Dementia		2 (7.7%)		-
Dementia (Not-specified)		2 (7.7%)		-
RAPA: Aerobic				
Sedentary		0 (0.0%)		0 (0.0%)
Underactive		3 (12.0%)		0 (0.0%)

Underactive regular-light activities	8 (32.0%)	8 (32.0%)
Underactive regular	2 (8.0%)	7 (28.0%)
Active	12 (48.0%)	10 (40.0%)
RAPA: Strength & Flexibility		
Strength	0 (0.0%)	0 (0.0%)
Flexibility	5 (20.0%)	6 (24.0%)
Both	3 (12.0%)	2 (8.0%)
Neither	17 (68.0%)	17 (68.0%)
EQ-5D Index (higher is better, Max 1)	0.7 (0.2)	0.7 (0.3)
Physical complaints that affect ability to perform physical activities: Yes	8 (30.8%)	6 (23.1%)
Worn an activity monitor (or similar) before: Yes	4 (15.4%)	3 (11.5%)

MOCA = Montreal Cognitive Assessment, RAPA = Rapid Assessment of Physical Activity

Table 2. Wear time data in people with dementia and carers.

	Person with dementia (n=25 ^a)				Carer (n=24 ^a)			
	M	SD	Min	Max	M	SD	Min	Max
Average daily wear-time (hrs/day)	23.1	2.6	11.4	24.0	23.8	0.4	22.1	24.0
Number of valid days of data								
≥ 13 hours wear-time per day	26.2	6.4	4.0	29.0	26.4	6.7	4.0	29.0

^aData from one dyad (person with dementia and their carer) could not be included because they wore the device for less than a day, another single carer refused to wear the device.

Table 3. Individual item satisfaction scores for the assistive device subscale of the QUEST
(Valid %).

	% Subjects 'quite satisfied' or very satisfied' (scores 4 and 5).	
	Person with Dementia	Carer
Dimensions	60%	40%
Weight	80%	72%
Ease in adjusting	82%	82%
Safe & Secure	88%	88%
Durability	88%	88%
Comfort	60%	56%

Table 4: Summary of qualitative themes and example quotes.

Category	Includes	Examples
Routine	Impact of wearing the device on routine.	<p><i>‘The only thing I had to get used to was wearing it in the shower and at night as I always take my watch off to go to bed and when I have a shower’ (P1)</i></p> <p><i>‘Well you’d never...why would you wear it [the device] in the shower? Because everybody knows you don’t have a watch in the shower... it was taken off because that’s what everybody does’ (C12 talking about P12)</i></p> <p><i>‘I think I noticed it more in, let’s say the first few days and have not been very bothered by it thereafter’ (P2)</i></p>
Design	Appearance, weight, materials, dimensions and comfort.	<p><i>‘[the device] being slightly rough on the edges and sticking out and I hope for a better design that would be less obtrusive. That’s all I think’ (P2)</i></p> <p><i>‘It is a bit bulky, that’s the thing that I would change if it were possible’ (P13)</i></p> <p><i>‘In terms of these machines, I think that the nice thing would be to have instant ability to see what the time is so that you don’t need this [indicates to watch] as well’ (P3)</i></p>
External Influence	The role of others in wearing the device.	<p><i>‘Well I must say not many people [commented], as I say, a couple, perhaps two or three said ‘Oh what’s that?’ and I said ‘Oh it’s something to measure your activity’ and they didn’t ask anymore’ (P25)</i></p>
Perceived benefits	The benefits of wearing the device, for themselves and for others.	<p><i>‘I think I was just curious and interested to see what the results would actually be when it comes off, you know, to find out whether it has been beneficial to the study and whether it will be beneficial to me when I know the results’ (P1)</i></p> <p><i>‘We are doing it because we want to help you but from a personal point of view it would be nice to get some information from what we’ve been doing’ (P3)</i></p>